

# National



# Haemophilia

Haemophilia Foundation Australia

[www.haemophilia.org.au](http://www.haemophilia.org.au)

No. 186, July 2014



# WFH 2014 WORLD CONGRESS, MELBOURNE!

# CONTENTS

- |    |   |    |   |
|----|---|----|---|
| 3  | From the President  | 19 | Recipes for healthy living                          |
| 4  | No worries: HFA and volunteers help make WFH congress a success     | 20 | Up close and personal                               |
| 5  | Our wonderful volunteers  | 21 | Reflections on the Psychosocial Day                 |
| 6  | Congress: an interview with Gavin Finkelstein                       | 22 | Buddy Awards launch                                 |
| 7  | GNMO Training   | 23 | Colouring in competition                            |
| 8  | Connecting worldwide  | 24 | Policy News   |
| 8  | Youth leadership, women, hep C and community attitudes to treatment | 25 | World Haemophilia Day 2014                          |
| 11 | MyABDR at Congress  | 26 | Red Cake Day - Haemophilia Awareness Week           |
| 12 | A nursing perspective   | 26 | 2014 'Changing Possibilities in Haemophilia' grants |
| 14 | Treatment Room  | 27 | Youth advocacy in action                            |
| 15 | A physiotherapy perspective   | 28 | Through the eyes of a Youth Fellow                  |
| 16 | Haemophilia and orthopaedics  | 29 | Youth at Congress                                   |
| 17 | Hearts and veins  | 30 | Youth news  |
| 18 | The importance of a healthy mouth                                   | 32 | Calendar  |

Cover images:  
WFH and HFA

Haemophilia Foundation Australia  
Registered No.: A0012245M  
ABN: 89 443 537 189  
1624 High Street Glen Iris,  
Victoria, Australia 3146  
Tel: +61 3 9885 7800  
Freecall: 1800 807 173  
Fax: +61 3 9885 1800  
hfaust@haemophilia.org.au  
www.haemophilia.org.au  
Editor: Suzanne O'Callaghan



## WFH 2014 WORLD CONGRESS

The World Federation of Hemophilia (WFH) 2014 World Congress was held in Melbourne, Australia, from Sunday 11 May to Thursday 15 May 2014.

4081 delegates from 128 countries attended what is the largest international meeting for the global bleeding disorders community – people with bleeding disorders and their partners and family, staff from haemophilia organisations, health professionals, government, industry and others with an interest in the area.

**“The thing I enjoyed most was the sharing of experiences, learning from different people from different countries and of course the knowledge that was imparted through the sessions.”**

Ricarte,  
Delegate from Philippines

In this issue of *National Haemophilia*, HFA delegates at the World Congress describe their experiences and give reports of meetings, workshops and presentations during Congress. ■



WFH 2014  
WORLD  
CONGRESS

Melbourne, Australia • May 11-15

Gavin Finkelstein is President, Haemophilia Foundation Australia

# FROM THE PRESIDENT

Gavin Finkelstein

## WORLD CONGRESS

**After a necessarily long build up to the Melbourne Congress it is amazing now that it is over!**

Our years of preparation stood us in good stead and we were able to hold up our end to support World Federation of Hemophilia (WFH) in this special event. I have no doubt those at the Congress will have taken away new information and ideas as well as having been challenged in so many ways.

It is not possible to attend a Congress without being touched in many ways by the experience of being part of the worldwide bleeding disorders community. I personally have returned home from Melbourne with a renewed commitment to our shared goal to Close the Gap to increase the supply and availability of clotting factor treatment and grow the reach of haemophilia care to the regions of the world where it is not yet adequate in anyone's terms and where there is so much more to be done. We will close that gap and those of us at the Congress know how important it is that we play our part in achieving this very important goal. As we work to complete our congress work HFA is very aware of its role in this and we will also play our part.

In this edition of *National Haemophilia* you will read about the experiences of people who attended the Congress from a range of different perspectives. They want to share their experiences with

those who were not able to attend the Congress and I hope we can bring you a flavour of the Congress and some of the important themes, information and challenges.

## NEW CLOTTING FACTOR SUPPLY CONTRACTS

The worldwide bleeding disorders community is facing challenging times; no less in Australia. With the recent announcement by National Blood Authority of new contracts for the supply of clotting factor for the next few years, some people will need to switch the brand of clotting factor they use for the treatment of haemophilia A. In these contractual arrangements the NBA has announced that Baxter is to be the preferred supplier of rFVIII through the supply of Advate, and Xyntha will also be supplied by Pfizer. The availability of KogenateFS supplied under the national contracts due to end 30 June 2014 will be phased out over the next 12 months. Those with haemophilia B will have a recombinant alternative for the first time as Baxter now has Rixubis registered in Australia for adults.

The new contracts bring some challenges for Haemophilia Centres and to the people who may have to switch products. HFA believes decisions about switching will be handled by Haemophilia Centres in a way that the clinical needs of each person with haemophilia will be put first and foremost. Our absolute

requirement is for patients and their clinicians to decide which product is best for them based on the best clinical evidence available. This is the most important priority, but we do understand the importance for governments to achieve competitive outcomes with their tenders as they have an imperative that the blood supply is not only safe and secure, but that it is affordable. We believe that there are many efforts in the blood sector which can contribute to achieving this, including initiatives such as My ABDR and various outcomes studies being proposed.

We are looking forward to the new longer acting clotting factors becoming available in Australia. We have already raised this issue with governments and health professionals and will be discussing how patients can access these products.

The recent Therapeutic Goods Administration approval in Australia of ELOCTATE, a long acting product for the treatment of haemophilia A, and ALPROLIX for haemophilia B, both manufactured by BiogenIdec has put this issue firmly on our agenda. It remains important to HFA that there is a range of treatment options including plasma derived and recombinant amongst the suite of products needed to treat people with bleeding disorders in our community to ensure everyone has access to the best product for their situation. ■



Jay Poulton is Editor/Editorial Services Coordinator, World Federation of Hemophilia

# NO WORRIES: HFA AND VOLUNTEERS HELP MAKE WFH CONGRESS A SUCCESS



HFA staff and Council delegates

Jay Poulton

Four years ago at the World Congress in Buenos Aires, members of Haemophilia Foundation Australia (HFA) started imagining what it would be like to have a Congress in their country. After many years of planning, organising and strategizing, that dream has come true.

For HFA Executive Director Sharon Caris, the reality hit on the first day of the Congress. "I walked into the foyer and saw the flags from all the different countries and I thought, 'Yes! This is a truly global organisation,'" she said. "People have been coming up to me and saying wow, so many stakeholders have come together to make this work.

The volunteers are coordinated by HFA Development Manager Natasha Coco and community members Bill Corbett, Carol Ebert and Heather Lauder.

The treatment centre and physiotherapy room also have a volunteer staff, coordinated by John Rowell, MD, Andrew Atkins, CPC, and Abi Polus, PT. "They have worked for more than 12 months to ensure all treatment needs are met," Caris said. Volunteers from every treatment centre in Australia are staffing the treatment rooms during Congress.

The Australian bleeding disorders community has also embraced the Congress, Caris said. More than 600 HFA members have travelled to Melbourne, including some people with severe mobility issues. "Some of them have never left their home states before," Caris said. "I think that really shows that we're all one big family."

Overall, Caris hopes that attendees from around the world have found the Melbourne Congress to be open, friendly and welcoming. "We wanted this week to be a happy occasion for everybody," she said. And it was an incredible success. ■

**"It is such a great honour and privilege to have the Congress in our country."**

said Caris. Australians from all walks of life have embraced the Congress. Case in point is the 85 volunteers who are staffing the Convention Centre this week. Only about half of them are HFA members or relatives of people with bleeding disorders. Others are members of the Melbourne community, including employees of the National Australia Bank.

"People both inside and outside of the community want to get involved - haemophilia truly is infectious," Caris said.



Congress volunteers

# OUR WONDERFUL VOLUNTEERS

Natashia Coco

My main role during the Congress was overseeing the group of wonderful volunteers, led by the three co-ordinators, Bill Corbett, Carol Ebert and Heather Lauder. Over the two weeks approximately 85 volunteers gave up their time to assist with jobs such as satchel packing, the meet and greet at the airport, giving people directions at the Melbourne Convention and Exhibition Centre, assisting in the treatment room and at the desk – the list goes on.

Before the Congress we prepared a volunteer manual which outlined the responsibilities of the various volunteers and the volunteers were invited to attend a training session before the Congress to learn about the Convention Centre and what they needed to do. Many volunteers had to walk several kilometres each day; many had repetitive jobs whilst others had jobs which changed for each of their shifts. Everyone who volunteered gave their time freely and generously and we are incredibly grateful that they made the congress run so smoothly. We have received messages over and over again about our volunteers and their approach to their jobs, the assistance they gave to delegates and most of all their welcoming and happy smiles.

Alain Weill, WFH President, wrote a special thankyou to volunteers highlighting this:

**“ Please accept our gratitude and appreciation for all the time that you gave and the cheerful and positive attitude that you brought to your role on sometimes long days. Thanks to you, the more than 4,000 delegates at the WFH World Congress had a positive experience and an unforgettable taste of true, ‘no worries’ Aussie warmth and hospitality.”**

I’d like to thank all our volunteers for being part of this once in a lifetime experience and add my special thanks to our co-ordinators Bill, Carol and Heather. 🍷



Left to right: Heather Lauder, Bill Corbett, Natashia Coco, Carol Ebert

## CAROL EBERT

Volunteer Co-ordinator

“It’s hard to believe that it has come and gone so quickly. I had the absolute pleasure of being involved in a working capacity at World Congress. I was one of the Co-ordinators for the 85 Volunteers who helped out. It was so inspiring to see all the different type of people who just want to help in some way, many who were not directly involved in the haemophilia community.”

## MIKE BARRY

HFA Life Governor and Congress Volunteer

“Volunteers were your personal friends who knew you but did not know a great deal about haemophilia. They are much wiser now about haemophilia and understand far better how you and your colleagues serve our haemophilia community. There were the distant and the close relatives. There were folk who had no direct connection with haemophilia including young men and women and these good stories rarely get told. There were the health professionals hidden in the treatment centre.....

Universally delegates expressed how successful the Congress had been and they wished to thank all of our volunteers for how helpful and friendly they had been and for their magnificent contribution to this event.”



Bill in action. Photo: WFH

# CONGRESS: AN INTERVIEW WITH GAVIN FINKELSTEIN

*Gavin Finkelstein, HFA President, spoke with Hannah Opeskin about Congress and his experiences there.*

**HO: What was the most interesting Congress session you attended?**

GF: I attended a session about the social impacts of having a bleeding disorder which I found particularly interesting as it discussed the amount of support and care family and friends provide to those with bleeding disorders and the impact on the whole family. The session covered topics such as a sibling's perceptions of the attention focused on a child with a bleeding disorder, and the large amount of time spent by the family attending medical visits and administering treatment. I thought that looking at social support from the point of view of those providing it rather than from those who require it was a different approach and is rarely discussed.

**HO: What sessions or topics would you like to have seen included or discussed in the Congress program?**

GF: Youth engagement is always a good but challenging topic to cover because haemophilia organisations typically find it hard to generate interest among young people. Although there were many sessions aimed at health professionals, there were several sessions specifically geared toward youth with bleeding disorders. A large number of Australian youth attended the Congress and these sessions were very popular amongst them. In fact, there were many Australian and International youth delegates attending sessions together and interacting with each other throughout the Congress.

**HO: What was your most memorable moment of the whole Congress experience?**

GF: From the moment I walked in, I thought it was an amazing feat to have four thousand delegates



Gavin in discussion with Michelle Sullivan from HFV at the Congress dinner

overcome the large distance and travel to attend the Congress in Melbourne. The weather, the large number of delegates and a comprehensive Congress program all contributed to the excellent atmosphere that surrounded the week. It was exciting to have so many people with similar interests in one place.

**HO: Were there many disparities between the lives of people with bleeding disorders in Australia compared to less well-resourced countries?**

GF: Limited access to treatment is always a major factor impacting on the lives of many who live in other countries. We are very fortunate to have the type of access we currently experience in Australia and that was

very evident throughout Congress. It was very apparent that the Australian young people attending Congress had fewer physical limitations than many international delegates. This emphasised just how lucky we are in Australia.

**HO: Congress highlighted an overarching goal of "treatment for all" but what do you think the biggest focuses are at the moment for the Australian bleeding disorders community?**

GF: Treatment for hepatitis C is still a large issue for adults with bleeding disorders across the nation including access to new treatments for those with bleeding disorders and hep C, and the support that is required alongside conventional treatment. ■

Shane Meotti is the Haemophilia Foundation Western Australia Committee Secretary and an HFWA delegate to the Haemophilia Foundation Australia Council

# GNMO TRAINING

Shane Meotti

In the days prior to the WFH 2014 World Congress in Melbourne I had the immense privilege of attending the WFH Global National Member Organization (NMO) Training on behalf of HFA. NMO Training provides a unique opportunity for national organisations to come together to discuss the issues and challenges facing our organisations and bleeding disorder communities and to share our knowledge and experiences. I was excited by the opportunity to attend NMO Training from the outset but I had no idea just how much of an impact it would have on me.

Training was held over 3 days from 8 - 10 May at the Novotel Forest Resort in Creswick, about 120km from Melbourne. Over 120 delegates, WFH Youth Fellows and WFH Executive Committee and staff from all over the world descended on Creswick on the day prior to training commencing. The location was stunning and the kangaroos and other native wildlife in the grounds and bushland surrounding the resort provided a truly Australian experience for the international delegates. By the time I arrived in the early evening the resort was buzzing as old friendships were rekindled and new ones started and going to dinner on that first evening was like walking into a huge family reunion.

## OVERCOMING CHALLENGES

We began the first day with a plenary session opened by Aris Hashim from the WFH Executive Committee. A session of laughter yoga by Bronwyn Roberts got everyone out of their seats and reminded of the positive power of laughter before Alain Weill, WFH President, continued the plenary with NMO sharing of best practices. We heard from 8 NMOs as they shared their experiences and achievements in building advocacy, youth and volunteer programs and other initiatives within their countries. The experiences shared by some of the NMO delegates were quite confronting and as I listened

I was struck by their incredible passion and determination to achieve great outcomes in the face of such challenges. As the morning progressed I realised that NMO training would not just be about developing skills and sharing information; it would be about awareness on a global scale.

## BUILDING SKILLS AND SHARING INFORMATION

The format of the training over the three days consisted of a half day plenary session and a half day workshop each day. For the workshops delegates were grouped according to whether their NMOs were emerging, established or from Spanish speaking countries.

In all I attended 9 plenary and workshop sessions and while they were all useful, the standout sessions for me were:

- NMO sharing of best practices (plenary 1)
- Youth leadership training workshop
- Women with bleeding disorders (plenary 2)
- Data and the economics of bleeding disorder care workshop.

Suzanne O'Callaghan from HFA facilitated the Youth Leadership Training workshop which explored ways to identify, train and sustain potential youth leaders in NMOs. The participation of the delegates and youth fellows and sharing of ideas made this a really engaging and motivating workshop and we all left with some great new ideas. I found the volunteer lifecycle case studies that we completed in our groups to be very insightful.

The Women with Bleeding Disorders plenary session was also very good and was very well received by delegates. Sonia Adolf, MD (Egypt), Arlette Ruiz Sáez, MD (Venezuela), Alison Street, MD (Australia) and Pamela Wilton (WFH executive committee) provided perspectives from established and emerging NMOs. Topics addressed included the basics of diagnosis,



GNMO Training delegates at Creswick. Photos: WFH



Laughter yoga

genetic counselling, treatment options and what NMOs are doing to incorporate women into their organisations.

In amongst the plenary sessions and workshops were great opportunities for networking and throughout the three days I had some wonderful conversations with people from all over the world - wonderful and inspirational people who have left a mark on me forever.

As we drove back to Melbourne on the Sunday to register for World Congress I wondered if it could be better than the 3 days I had just experienced. On reflection they were two very different experiences and both experiences of a life time. Global NMO training and World Congress have really opened my eyes to a lot of issues that exist globally for people with bleeding disorders. At the same time however I see a very positive future knowing that we have so many passionate, committed and clever people across the world striving for the best outcomes. ■

Dan Credazzi is Vice-President,  
Haemophilia Foundation Australia

## CONNECTING WORLDWIDE

*Dan Credazzi*

The Global NMO (National Member Organisation) training was the best chance in my life to get to know people with bleeding disorders and parents from a different part of the world. Fortunately, those I met have kept in touch and we have new friends from Nepal to Belgium.

We caught up with our Thai Twinning partners and their patient group has made great progress since our HFA team finished the twinning program with them three years ago.

As expected, I was reminded of how harsh and short life is without diagnosis and treatment. The global gap in treatment for all is wide, but it is actively narrowing as laboratories are developed where they've never existed before. Everything starts with diagnosis. Other countries in the developing world do envy our care position here in Australia.

I'm grateful to have been offered the chance to attend the WFH NMO training and hope that our son will be able to attend similar meetings when he gets older and more involved in the global bleeding disorders community. There is so much work to do. 

Suzanne O'Callaghan is Policy Research and Education Manager,  
Haemophilia Foundation Australia

# YOUTH LEADERSHIP, WOMEN, HEP C AND COMMUNITY ATTITUDES TO TREATMENT

*Suzanne O'Callaghan*

### YOUTH LEADERSHIP TRAINING

Being a facilitator at the National Member Organisation (NMO) training was a new experience for me. My role was to facilitate a workshop on youth leadership training with a group of representatives from established haemophilia organisations around the world, some like Australians who had ready access to clotting factor treatments, while others did not. However, they all had in common a real desire to move forward with training and sustaining their young leaders.

This was a strong, thoughtful and articulate group who – although they came from very different backgrounds and English may not have been their first language - worked through:

- The life stages of volunteering and how younger and older volunteers could help each other – with energy and ideas, mentoring, support, wisdom, skills, connections.
- What makes a good leader – at any age.
- Creative and ingenious plans for identifying, training and sustaining young leaders.

Among the group were three HFA Council delegates – Dan Credazzi, Shane Meotti and Michelle Sullivan - and several WFH Youth Fellows, including Tim Demos from Melbourne. The Youth Fellows took the opportunity to help older participants understand the way young people communicate (use their language and social media tools!) and like to participate and be acknowledged in haemophilia organisations.

### There were two presentations:

- Courtney Stevens, the HFNZ Youth Fellow, talked about HFNZ's development of young people, giving them both some autonomy as well as a framework to work in.
- Dawn Rotellini from the USA spoke about the National Hemophilia Foundation's National Youth Leadership Institute, and the benefits of its formal application process in helping young people to step up and take a lead role in projects.

I am still amazed by the depth of discussion and I look forward to sharing what I learned with my colleagues. I hope the rest of the group found it as inspiring as I did!

## The next generation: a leadership and mentoring program for young people with bleeding disorders

Suzanne O'Callaghan, Australia

I also had the opportunity to make a short presentation on HFA's youth leadership training during Congress. This was most memorable for the question time, when some of Australia's youth leaders who had attended training came to the microphone to answer the questions and were evidence of the active and confident role they can now take.

## EMBRACING WOMEN'S SEXUALITY

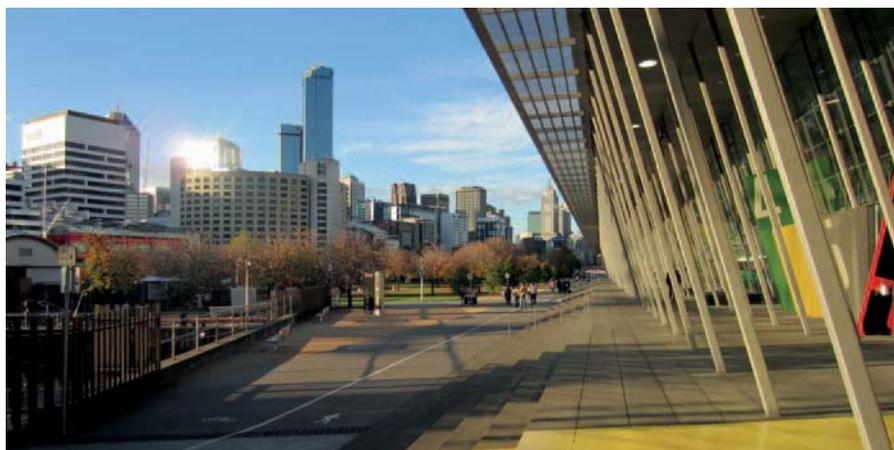
Chair: Sharon Hawkins, Australia

Claire McLintock, New Zealand; Jill Smith, Australia; Lisa Thomas, USA

### How do women with bleeding disorders manage their sexuality?

Claire McLintock, a haematologist and obstetric physician from New Zealand, walked through current treatment options and combinations for women with bleeding problems, and in particular, where pregnancy is a goal compared to when it is not. She explained that the terminology has changed to be more specific – for example, “abnormal uterine bleeding” rather than “menorrhagia”, with a focus on quantity, duration and timing to clarify what is normal.

Reporting on a series of interviews with women in South Africa, Jill Smith's presentation looked at the nuances of women's relationships with their partners and its impact on their sexuality and relationships – their shyness about discussing it



MCEC entrance

with partners, embarrassment when someone else notices their bleeding before they do, and concerns about giving birth.

Intimacy and self-esteem were the themes for the final speaker, Lisa Thomas, who is a social worker and marriage and sex therapist from the USA. She set simple goals for a relationship:

- Communicating what works for you
- Accepting that it is OK for you and your partner not to be sympathetic all the time
- Work on a relationship – aim to be intimate physically at least once a week
- But this can be about pleasure, rather than performance
- And tips about being prepared, such as using dark sheets or menstrual cups.

## Made in Canada – Code Rouge

Shelley Mountain, Canada

I was also interested to catch up with the Canadian Hemophilia Society's Code Rouge program for women ([www.coderougewomen.ca](http://www.coderougewomen.ca)) with their online information for women with bleeding disorders and Ambassadors, trained speakers who tell their personal story and encourage other women to connect and learn more about their health. I had already been in contact with them about HFA's women's project – they are happy to share their information and what they have learned and I think will be a valuable connection for us as we put together our women's resources.

## HEP C TREATMENTS

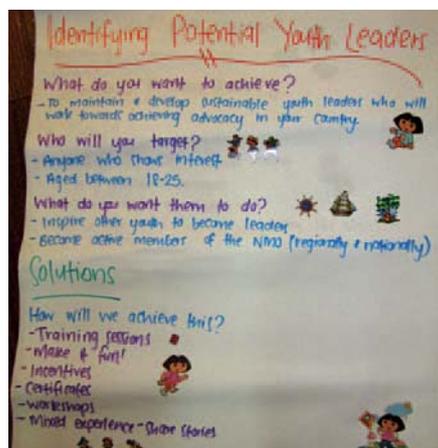
### New approaches to hepatitis C management

Catherine Stedman, New Zealand

One of the most exciting sessions for me was the presentation about new hepatitis C treatments. Catherine Stedman, a gastroenterologist and hepatologist from New Zealand, outlined the results of large clinical trials with second wave direct acting antiviral (DAA) drugs. These have had higher success rates, fewer side-effects, shorter treatment courses, and some have been interferon-free and all-oral regimens (ie, tablets rather than injections).

People with bleeding disorders and hepatitis C often have particular needs for treatment – living with long-term infection, they may have already had unsuccessful treatment or severe side-effects with pegylated interferon/ribavirin, some may have more advanced liver disease, some may have “harder to treat” genotypes, such as genotype 1.

With the variety of new combination treatments available, clinical researchers have been able to find safe and successful treatment regimens for many more people with special needs, including for people with cirrhosis. To achieve this, some individuals required a triple therapy of the DAA with interferon and ribavirin, others an interferon- or ribavirin-free combined therapy with other new DAAs, or a longer treatment course (eg, 24 weeks rather than 12).



GNMO Training flipchart

Ironically, genotype 3 appears to be the genotype that responds less well to these interferon-free treatments and may require a longer course of treatment. More new DAAs are being tested and optimal treatment regimens are still being evaluated.

How safe and effective are these new treatments for people with bleeding disorders? Often people with bleeding disorders are excluded from clinical trials, so it was very interesting to see the results of one small clinical trial in 14 people with HCV genotype 1 and a bleeding disorder (haemophilia A and B and von Willebrand disease). They were treated with two new DAAs, sofosbuvir and ledipasvir, and ribavirin for 12 weeks. There were only mild side-effects and 100% successfully cleared HCV. While this was only a small trial, it is encouraging to see such good results.

#### Further reading:

A summary of Stedman's presentation is on page 130 in the State of the Art edition of Haemophilia journal (in Congress delegate satchels):

Kulkarni, R, Mauser-Bunschoten, EP, Stedman, C, Street, A. Medical co-morbidities and practice. Haemophilia 2014;20(Suppl. 4):130-136.

Read it online  
[www.tinyurl.com/stedman-hep-c](http://www.tinyurl.com/stedman-hep-c).

### THE FUTURE OF HAEMOPHILIA CARE: UNDERSTANDING GLOBAL DEMAND FOR TREATMENT

Chair: Mark Skinner, USA

David Page, Canada; Jeffrey Stonebraker, USA; Randall G. Curtis, USA.

HFA is often called upon to represent the Australian bleeding disorders

community in relation to treatment and with the new treatments coming on to the market, this is becoming increasingly complex.

Mark Skinner, former WFH President, began this session with a call to the bleeding disorders community to influence the way treatment and care is going forward. In the USA and Europe patients are now involved at the planning stage for research studies and can help to give some direction to the treatment outcomes that are investigated.

With the new longer-acting treatments, what are the right treatment goals for someone with haemophilia now?

- To reach a moderate, mild, "normal" severity?
- Increased bleed protection?
- To treat less often?

Where this may be a trade-off, it is important to have a sense of community preference.

#### Patient attitudes survey results

David Page, Executive Director of the Canadian Hemophilia Society, reported on a multinational survey of patient attitudes to treatment carried out in Canada, USA, Ireland and Australia. Some of you may recall completing the survey.

- Overall 195 people completed the survey, 34 in Australia
- Only a few found their infusions difficult
- Most were more interested in improvements to reducing

frequency of treatment than effectiveness of the treatment in controlling the bleeds.

The speakers who followed David Page commented on the way that demand for treatment is modelled for "payers" – the organisations in each country that subsidise treatment: in the USA, this is often health insurance companies; in Australia, the government. Modelling is often based on dose, frequency and the number of bleeding episodes – and increasingly is taking compliance with treatment into account.

An energetic discussion at the end of the session debated whether the importance of protecting the population against bleeding is being downplayed.

Or would a user-pays approach to patient bleeding outcomes be put in place, eg if you want to play a high risk sport, you need to pay extra for treatment?

Experts including Albert Farrugia joined the debate, discussing whether it can be demonstrated that low factor trough levels during longer-acting treatment impact on bleeding episodes – and a parent commented that when their child participated in a clinical trial of longer-acting treatment it worked well for the child and increased their quality of life.

It is clear there is still research required to understand clinical and quality of life issues – and equally clear that the patient community has a vital interest in the way this research progresses! #

# PATIENT TREATMENT ATTITUDES SURVEY

If you or your child has haemophilia, there is still time to have your say about future treatments.

HFA is participating in the multinational Patient Attitudes Survey (see the report by David Page above).

So far there have been 34 responses from Australians – it would be great to have another 20-30 to make the results more meaningful.

The survey is open until **31 July 2014** to collect more responses before publishing the results.

Visit the News on the HFA website to complete the survey [www.haemophilia.org.au](http://www.haemophilia.org.au) #

# MYABDR AT CONGRESS



*Suzanne O'Callaghan and Peter O'Halloran*

With more than 600 Australian delegates and a very interested worldwide community, it was always going to be important for MyABDR to have a presence at the World Congress. But in the end it was a bigger splash than we anticipated!

## MYABDR POSTER

HFA and the National Blood Authority (NBA)'s collaborative scientific poster on MyABDR was accepted for poster presentation at Congress. With its diagrams of how the system works and screen shots, the poster generated a lot of in-depth discussion with haematologists and industry from around the world.

## BEYOND REGISTRIES: INTEGRATED INFORMATION SYSTEMS

*Chair: David Page, Canada*

*Kevin Ryan, Ireland; Peter O'Halloran, Australia; Randall G. Curtis, US*

Worldwide there are a variety of personally controlled systems for people with bleeding disorders to integrate their home treatment and inventory information with the clinical system at their Haemophilia Centre. This became the focus of a session that explored three different systems – the Irish National Haemophilia Electronic Patient Record, the American Thrombosis and Haemostasis Network, and the Australian MyABDR.

All three speakers highlighted the importance of simple systems that can be used on an individual's normal handheld device, such as their smartphone. They also emphasised

the potential to provide significant clinical information both to the person's Haemophilia Centre for their care and for de-identified research data to create better treatment outcomes for the wider community of people with bleeding disorders. Energetic discussion followed the presentations, with questions about:

- How to convince patients that there are benefits in completing the data in these systems.
- Reminding patients that, if there are bleeding problems, completing data during a bleed is not the same as a phone call to the Haemophilia Centre.
- How to make the collected de-identified data available to the patients who use the system.

"The strong interest in both the technology and community engagement methodology adopted in the development and implementation of MyABDR from a range of other countries was both surprising and rewarding. The seamless link between ABDR and MyABDR enabling the ready exchange of information from both a hospital and non-hospital setting was commended by many international clinicians and people with bleeding disorders," said Peter O'Halloran from the NBA, who presented the MyABDR system at this session.

## NBA BOOTH

The spotlight was on MyABDR at the NBA booth in the Trade Exhibition. The team had online access to the MyABDR system as well as printed

educational materials and the very popular MyABDR stress phones – so with more than 270 Australians with bleeding disorders registered on the system, they were kept busy helping current MyABDR users with their questions, showing new features, trouble-shooting and registering new users on the spot. #

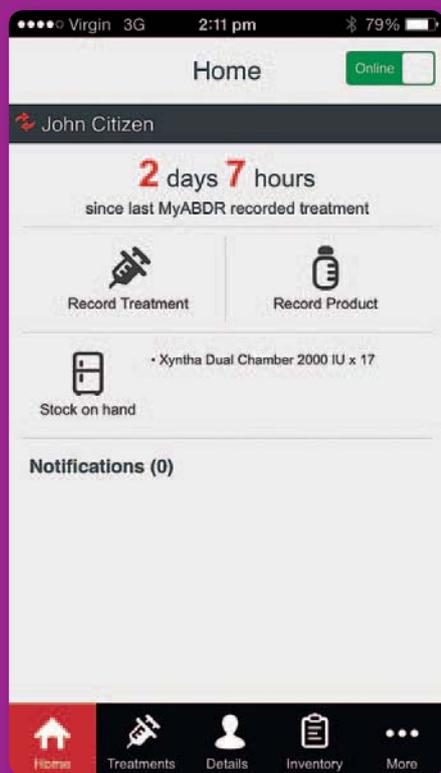


## MYABDR WINS iAWARDS

In a decisive acknowledgement of a very successful collaboration, MyABDR received three of the seven ACT State iAwards in June 2014. The iAwards honours the best and most innovative solutions and inspirational companies and individuals in the ICT Industry.

As a State Winner, MyABDR will now progress to the National iAwards in August 2014. #

# HAVE YOU REGISTERED YET?



MyABDR is now available to use. You can register online and get started!

MyABDR links directly to the Australian Bleeding Disorders Registry (ABDR), the system used by Haemophilia Centres for clinical care of their patients.

## HOW TO REGISTER

- Download the MYABDR app from Apps store (Apple) or Google Play (Android) or go to [www.blood.gov.au/myabdr](http://www.blood.gov.au/myabdr).
- Register online on the app by CREATING AN ACCOUNT.
- Or register on the MyABDR web site at [www.myabdr.blood.gov.au](http://www.myabdr.blood.gov.au) by clicking on NEW USER? [CLICK HERE TO REGISTER](#) (easier to complete the form on the web site!)
- After you register, your Haemophilia Centre will process your access to MyABDR
- After approval you will receive an sms with a temporary password and an email telling you that your account has been activated. You can now start using MyABDR.

If you have already registered, but aren't using MyABDR yet, what are you waiting for? Our feedback has been that it REALLY is quick and easy to use.

## START UP PACKS

Instructions on getting started with MyABDR can be downloaded from [www.blood.gov.au/myabdr](http://www.blood.gov.au/myabdr). Printed copies are also available from your Haemophilia Centre or HFA – phone 1800 807 173, or email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au).

## NEW FEATURES

Watch out for new releases of the MyABDR app with great features this year. There has been one already – which included a function to upload photos via the notes field. Just update the app on your phone when it tells you there is a new release.

If you have registered with MyABDR, you should also have received a feedback survey – your answers will help with the next steps of development. <#>

Dale Rodney is the Haemophilia Clinical Nurse Consultant, Haemophilia Treatment Centre, Calvary Mater Newcastle, NSW

## A NURSING PERSPECTIVE

*Dale Rodney*

It was recently my great privilege to attend the biennial World Federation of Hemophilia (WFH) Congress – the first to be hosted by Australia. This also happened to be my first official haemophilia conference since taking up my current post in January 2013 at the Calvary Mater Newcastle.

Since the last WFH congress in the city of Paris in 2012, there has been an almost palpable level of excitement and anticipation leading up to 11 May this year when it was Melbourne and Australia's turn.

The Melbourne Exhibition and Convention Centre (MCEC) located on the banks of the Yarra River was a stunning venue for this gathering of those whose lives are either affected by a bleeding disorder in some way, as well as the many important professional groups who represent the comprehensive care team for persons with bleeding disorders and their families.

The Congress opening ceremony featured a traditional aboriginal welcome and dance performances

which were warmly received. Following this was a rather impressive cocktail reception which provided an opportunity for all to mingle, relax and meet new people.

The cultural evening on the Tuesday night was well attended and gave delegates a "taste of Australia" with not only great food, wine and beer from around Australia, but some roaming "Aussie" animals (the dressed up human kind!) to entertain the crowd and provide "one of a kind" photo opportunities.

## NURSES' WORKSHOP: FROM TRIAGE TO TRIUMPH

As expected, the congress featured a full program beginning on the Sunday before the start of the congress with the Nurses' Workshop. This workshop included discussions about the benefits of Telemedicine – significant in the ever-increasing shift to outpatient care, and instrumental in improving care for patients and families living with a bleeding disorder in regional and remote areas. Topics such as the successful use of telephone clinic protocols in Canada, the current era of electronic record keeping (E-Logs) via social media, smart phone/computer applications to enhance patient care and outcomes, and a presentation on sustaining haemophilia nursing positions within an activity based funding environment also covered very relevant and interesting points and gave rise to plenty of interactive discussion.

## CONGRESS SESSIONS AND POSTERS

There was of course a large variety of concurrent sessions daily to choose from with the usual lunchtime and evening Symposiums. The quality and breadth of the presentations was impressive, and attempting to fit in as much as possible from as many sessions as possible was a daily challenge. The sheer size and layout of the MCEC ensured that between sessions delegates, either willingly or unwillingly, got their daily exercise!

The poster presentations for WFH congress numbered 237 with an astounding variety of subjects and studies covered, and the trade exhibition area was also consistently busy, providing the opportunity to speak with those in the field and hear about the latest innovations, review and collect resources, and for many just relax with a coffee in between sessions.

## Challenges and solutions in haemophilia B treatment adherence – Focus on adolescents

*Regina Butler, USA  
(Industry symposium)*

Of the many interesting presentations during congress, this was one that I particularly enjoyed.

An important question was raised. "Non-adherence – whose fault is it?"

It has been identified that health care providers can unwittingly contribute to treatment non-adherence by their patients by the following means:

- Not acknowledging the patient's lifestyle and how treatment impacts on this.
- A sub-optimal relationship between the patient and health care provider.
- The complexity and duration of the treatment protocols or regimens the patient is encouraged to adhere to, and symptom relief (in the setting of acute bleeding) vs prevention (prophylaxis).

Challenges involving the level of skill in relation to venous access, cost, and overprotective parents and Haemophilia Treatment Centres, can also act to delay the adolescent's desire or motivation to take responsibility for managing their haemophilia.

Adolescents are generally powerless in chronic health situations. They are often inconsistent in their ability to think formally, and crave peer acceptance - not wishing to be different. Both anxiety and depression are also well recognised in the general adolescent population whether they are living with haemophilia or not, and this has been identified as a potential barrier to adhering to routine treatment.

Also acknowledged by other speakers on the same subject was:

- Addressing the problem of non-adherence via thorough assessment.
- Identifying perceived or actual barriers to treatment adherence.
- Providing education and encouraging constructive dialogue between patient and healthcare provider.



Dale Rodney

- And adopting and applying multi-dimensional strategies to encourage adherence including behavioural change.

This session reinforced for me the multifactorial nature of treatment adherence and how we, in partnership with our patients, can improve the treatment process and enhance favourable outcomes.

By developing an individualised plan of care for the patient with a factor IX deficiency to work around issues and advocating for and empowering the adolescent, significant improvements in treatment adherence are practically possible.

Finally, this was a most successful congress and I believe all involved certainly did Melbourne and Australia proud! I am sure that we will all be talking about the experience for a long time to come. ■

# TREATMENT ROOM

“During congress, WFH provided a treatment room where those needing assessment or access to clotting factor concentrates were managed by volunteer nurses, physicians and physiotherapists from the Australian Haemophilia Treatment Centres – operating on a roster basis. WFH volunteers did a fantastic job manning the treatment room front desk and triaging patients requiring treatment or assistance.

My brief experience in the treatment room was most fulfilling and a great opportunity to meet delegates with bleeding disorders from all over the world and learn a bit about their experiences compared to us here in Australia.”

**Dale Rodney**  
haemophilia nurse, Newcastle

## TREATMENT ROOM CO-ORDINATORS

Andrew Atkins and Abi Polus were responsible for setting up the treatment room with relevant equipment and rosters for the nurses and physios – a role which took much hard work and dedication.

“It proved to be a great opportunity for the volunteers from all around Australia to work together to support people while they were attending

the Congress – but the real reward was forming a unique bond for a brief time with people living with a bleeding disorder from around the world and hearing first-hand accounts of their experiences.”

**Andrew Atkins**  
haemophilia nurse, Adelaide

“It was quite a revelation and a snapshot of a global perspective of haemophilia working in the physiotherapy room. Patients ranged from those who had had adequate factor availability throughout their lifetime to those who had never, ever had any access. What was most fulfilling was that we could send almost every patient who came to see us away with basic advice, a plan of management and an exercise program or a direction to access one for suggestions of how they could improve their muscles and joints, and in this way improve their day-to-day function and possibly decrease their bleeding.”

**Abi Polus**  
haemophilia physiotherapist, Melbourne

## TREATMENT

The treatment room was used to assist people who were having

bleeding episodes or who needed help with clotting factor concentrate infusions.

Some people treated themselves with the personal clotting factor supplies they had brought with them. Where this was not an option, the treatment room also had stocks of humanitarian donations of clotting factor given to WFH by product manufacturers. Making donated product available took considerable preparation. Dr John Rowell from the Queensland Haemophilia Centre and Sharon Caris from HFA liaised with WFH, the Therapeutic Goods Administration (TGA) and the Australian Quarantine and Inspection Service (AQIS) over a couple of years to make sure there were adequate supplies of clotting factor and that the regulatory and customs requirements were met for the donations and to ensure overseas visitors to Australia had relevant and timely information about bringing their personal supplies of clotting factor to Australia with them.

Dr Rowell coordinated the roster of doctors from around Australia who had volunteered to provide their services to the people with bleeding disorders who used the treatment room. ■



“Thanks to friendly treatment room team” – Congress delegate and Australian volunteer nurses

# A PHYSIOTHERAPY PERSPECTIVE

Juliana Dias

Attending the International Congress in Melbourne was great. In fact it is hard for me to pick a favourite topic from the Congress to write about because I discovered so many new aspects including diagnosis and treatment of social issues. Here I have presented some of the topics that I found most interesting.

At the opening ceremony, Megan Adediram from Nigeria presented on her years of suffering due to her two children with haemophilia who had no access to treatment. Incredibly, they only received assistance after she wrote more than 60 letters to people and organisations around the world to assist them, thanks to the "Cornerstone initiative" program. That was a clear example of how much a mother would do to overcome obstacles for her children and the strong commitment of the World Federation of Hemophilia which aims for "treatment for all". Her unscripted speech was very emotional and it also seemed to make a deep impact on the rest of the audience as well.

## TRANSITIONAL LIFE EVENTS

In one of the psychosocial professional development sessions, Frederica Cassis from Brazil also gave an excellent presentation. It was on how to work with children who have experienced critical transitional life events, such as pain and other life-scarring events for children. In 2004, Frederica created 'educational playing cards' to explain issues like blood clotting, self-infusions and treatments, which are now available on the World Federation of Hemophilia website ([www.wfh.org](http://www.wfh.org)).

Similarly, Sylvia Von Mackensen from Germany explained how people with haemophilia go through different phases when they are considering disclosing this to their partners, preparing to get married, have children etc. She also provided some useful suggestions on how to manage these situations. It was very interesting and an eye-opener for a range of associated social issues **that, as someone new to the area, I may not ordinarily consider.**

## JOINTS AND BLEEDS

From the vast array of interesting Free Paper sessions during the Congress, two that I really enjoyed were from the "Outcome assessments and clinical issues and trials" session. Firstly, the reliability study in Haemophilia Joint Health Score (HJHS) showed that different physiotherapists were reliably able to carry out the assessment and get the same joint score results. Second was a comparative study of people with haemophilia from a developing and developed country. The study **was useful evidence to demonstrate** how people who had lifelong prophylaxis from an early age in a developed country had better activity levels, quality of life and HJHS compared to those from developing countries who had on-demand treatment for years.

Kathy Mulder, an experienced haemophilia physiotherapist from Canada, reminded us that sometimes an injury is not necessarily a bleed. Rather, people with haemophilia can have other injuries like tendinitis, arthritis and so on.



Megan Adediram at the Opening Ceremony  
Photo: WFH

Due to prophylaxis some people may never appear to experience a bleed, yet damage still occurs.

Another notable aspect for physiotherapists from the Congress is that, if we look into the future, ultrasounds may play an important role in clinical examinations for acute joint bleed in order to manage, treat and improve patient outcomes, as presented by another Canadian physiotherapist.

To sum up, the Congress gave me an extremely valuable opportunity to learn new things and also a sense of how much we can help people, motivating me to do even more to help in Canberra.

I would like to acknowledge the support received to attend the congress from Haemophilia Foundation Australia, Haemophilia Foundation ACT and ACT Health. ■

# HAEMOPHILIA AND ORTHOPAEDICS

Cheryl Ellis

I was fortunate enough to attend the 31st World Hemophilia Congress in Melbourne this year.

I found most of the plenaries and session descriptions most interesting, and was often undecided as to which ones I would choose to attend. The majority of the sessions I attended related to family issues, novel treatments, ageing with haemophilia, pain, prophylaxis and the future of haemophilia treatment.

## BACK TO BASICS

*Chairs: Nicholas Goddard, United Kingdom; Angela Forsyth, USA*

*Alison Street, Australia; Lize Van Vulpen, The Netherlands; Nichan Zourikan, Canada; Marvin Gilbert, USA.*

This was the first session I attended, which included an informative talk by Dr Alison Street named *Haemophilia 101*. I especially liked her straightforward explanation of the differences between primary, tertiary and secondary prophylaxis, and on-demand treatment. Dr Street discussed what is happening now and things that are upcoming, including individualised/ tailored treatment plans and care, cheaper products, the availability of longer-acting products, and increased availability of products internationally. An increasing focus on women with bleeding disorders, including symptomatic carriers and women with factor levels that indicate mild haemophilia, the importance of genetic testing, and the importance of good data collection in forms such as patient diaries and pharmacokinetic studies, were also discussed by Dr Street.

Lize Van Vulpen covered the pathogenesis of haemophilic arthropathy. She illustrated how synovial, cartilage and bone changes occur within joints that have experienced a bleed. The synovium functions to produce synovial fluid, which nourishes and lubricates the

joint and removes debris and blood from the joint space. Synovial tissue is highly vascularised. Synovial changes result in iron deposition, inflammatory responses and adaptational changes such as neovascularisation. This revascularisation is often very fragile, possibly resulting in further bleeding into the joint. Blood disturbs the cartilage matrix turnover, and results in further inflammatory changes and chondrocyte apoptosis (destruction). Bone changes that can possibly occur include epiphyseal enlargement, subchondral cysts, and osteoporosis due to decreased physical activity and co-morbidities (such as hepatitis and HIV). Detrimental bone changes will occur in less than 14 days of a major joint bleed. More bad news is that joint bleeds are possible even whilst on prophylaxis.

Nichan Zourikan spoke about the role of physiotherapy in haemophilia. The main goal is to pro-actively reduce or prevent future bleeds. He also talked about the differing availability of resources from country to country, and reinforced the importance of tailoring treatment for each person. The steps of effective post joint bleed treatment include patient evaluation, factor treatment for three to four days post-bleed, and RICE (rest, ice, compression, elevation). Adequate factor treatment stops bleeding but does not accelerate healing. Rest should include total rest on day one, and four to five days of non-weight bearing. Ice helps to reduce pain, compression and elevation helps to reduce swelling and blood in the joint.

Exercise is advised, as it increases muscle strength and bone density, improves cardiovascular health, decreases cancer risk, and improves blood sugar and cholesterol levels. Zourikan advised that patients with chronic synovitis should avoid repetitive impact activities, such as running on hard surfaces.



Cheryl Ellis relaxing with other HFWA delegates  
Photo: Cheryl Ellis

Nicholas Goddard lectured about orthopaedic surgical options in haemophilia. He espoused the importance of a team approach, including the haematologist, nursing and physiotherapy staff, surgeon and patient. The ideal scenario would be to adopt a conservative approach where possible, but perform joint replacements early if necessary. The goals of surgical intervention are to provide relief from pain, restore function, reduce bleeds, and promote independence. All of these goals ideally result in an improved quality of life.

## CONGRESS CONNECTIONS

There were numerous delegates from all over the world staying at the same hotel where I was (Travelodge Docklands); and one of my most memorable conversations was occurred whilst I was walking from the hotel to the Melbourne Convention and Exhibition Centre with a doctor from Bangladesh. He was most interested to hear about my two boys (who have severe haemophilia A), their diagnoses and prophylaxis regimes. I was saddened to hear about the scarceness of on-demand treatment, let alone prophylaxis, available to his patients back home. This encounter reinforced for me the over-riding message of the Congress - "Close the Gap".

The Congress was a great place to meet and share information and experiences with other families and health professionals from all over the world who have something in common with us – they are affected by a bleeding disorder, or strive to improve the lives of those who are. If you get a chance to attend a National Conference or World Congress, grab the opportunity! #

David Stephenson is a Haemophilia Foundation Australia Council Delegate and President, Haemophilia Foundation Queensland

# HEARTS AND VEINS

David Stephenson

Melbourne in autumn where delegates from all over the world met with one goal - to share information and experiences and to grow better outcomes for those with bleeding conditions: this is my take on several presentations across the event I found particularly interesting.

## Cardiac risk factors in older patients with haemophilia

Leonard Minuk, Canada

This presentation explained that people with haemophilia (PWH) are now approaching the life expectancy of the general population but there is little current evidence-based data for doctors to use when confronted with cardiac issues. This will come in time with international experience.

Minuk explored the issues around heart disease research in PWH. In some studies PWH appear to have a slightly lower risk of heart disease compared to the general population, but there is controversy about this with some other studies indicating the opposite: we will have to wait for large population studies of older people with bleeding disorders to understand this better. Another question for future clinical research is what influence longer-acting products might have with higher levels of factor in the blood for longer - could this counter to some degree the possible protective benefits of having a bleeding condition and change cardiac risk factors?

What does appear to be in general agreement are the risk factors for PWH, which are thought to be the same, or higher, than the general population:

- High cholesterol
- High blood pressure

- Diabetes and ageing.

The key message was – get yours checked!

The presenter suggested that your GP and Haemophilia Treatment Centre work proactively together with you to manage not just cardiac but other comorbidities to share their expertise.

## THEIR MESSAGES FOR PREVENTION?

- Stop smoking - quit today and live!
- Prevent obesity - check your BMI
- Blood pressure - check and manage
- Cholesterol - check and manage
- Physical activity - work with your physiotherapist; even small effort works.

## VEIN HEALTH

Chair: Regina Butler, USA

Mahmoud Abu-Riash, Saudi Arabia; Sherry Hubble, USA; Virginia Puligia, Italy.

I was interested to see in this session that people with haemophilia (PWH) are actually listed as a risk factor for venous access in a condition called DVA - difficult venous access. I imagine we can all relate to times when locating a vein can be frustrating and stressful. The session was a discussion of vein access and the associated issues aimed at nurses but I found the information very useful.

The best veins are often not visible or easily felt but the presenters commented that each poke is a learning experience and you get better at it. Accessing veins as a patient or practitioner can be



Photo: Cheryl Ellis

challenging when you have issues of age (young and old), dark skin, pain, scar tissue, obesity and even a phobia or anxiety.

## THE PRESENTERS' TIPS WERE:

- Use the smallest needle size possible for the situation.
- Grip and release hands with the tourniquet on.
- Warm packs can help dilate veins and make them more visible.
- Gentle slapping of the vein can help.
- Choose a vein that is easily compressible.
- Don't tell a child it won't hurt.
- Stress the need for hydration beforehand as this increases volume.
- A level of exercise can assist in showing up veins.
- Numbing cream can assist but takes time.
- An alternative to a tourniquet is a blood pressure cuff or even a clip on 'boa constrictor' that you then roll down the arm but caution is required for elderly as this can pop veins with the extra pressure.
- With babies you can use a torch to shine through the skin to show up veins.
- Ports and PIC lines are options but there are risks of infection to consider.
- A practical approach that body builders use is to make a fist or grip or compress a spring to build muscle and in the process veins are significantly improved - talk to your Physio.

And of course, if you have any questions, issues or concerns talk to your Haemophilia Centre. ■

# THE IMPORTANCE OF A HEALTHY MOUTH

Tim Crowden

I don't think many of us enjoy going to the dentist. But deep down we all know that maintaining a healthy mouth and preventing dental problems is important – not only to quality of life and nutrition, but to avoid invasive dentistry and the inherent dangers of surgery.

This is particularly important for children and adults with haemophilia and related bleeding disorders.

## THE COST OF POOR ORAL HEALTH IN CHILDREN WITH BLEEDING DISORDERS

*Chair: Alison Dougall, Ireland*

The WFH 2014 World Congress devoted some time to this issue – speakers from Ireland, Serbia, Japan, China, Turkey and Canada provided complementary sessions.

Dr Kirsten FitzGerald from Ireland gave an excellent and comprehensive presentation with useful recommendations and tips.

She explained that the main aims of dental management with children and adults with haemophilia and related bleeding disorders are:

- To prevent gingival disease and dental caries so as to preserve the teeth and maintain a healthy mouth; and
- To carry out dental extraction when this becomes necessary, as safely as possible.

Oral disease may affect general health and may cause serious bleeding. Tooth extraction and some local anaesthetic (LA) injections can cause bleeding that persists for days or weeks and that cannot always be controlled by pressure alone.

Unfortunately, children and adults with haemophilia and related bleeding disorders may neglect oral health for fear of bleeding; this has contributed to a lack of good dental care for some.

### So what to do?

If you or your child has haemophilia, you can attend a 'normal' family dentist for check-ups, sealants, most fillings, braces and cosmetic treatments including cleaning of teeth, tooth whitening and fluoride treatments. However, children and adults with haemophilia and related bleeding disorders and their dentists must be aware that local anaesthetic regional blocks, lingual infiltrations or injections into the floor of the mouth must not be used in the absence of factor VIII replacement – the risk of haemorrhage hazarding the airway and, potentially being life-threatening, is high.

As with all things relating to haemophilia and related bleeding disorders, awareness is key. Before making an appointment, touch base with your haematologist or the Haemophilia Treatment Centre (HTC) – they will be able to provide a letter for your dentist or orthodontist. Also remember to make dental appointments in the morning, in the rare occasion that there is a complication.

If your dentist or orthodontist is unsure of where to look for guidance, FitzGerald suggested steering them towards the WFH Guidelines for Dental Treatment of Patients with Inherited Bleeding Disorders or the WFH Dental Management of Patients with Inhibitors to Factor VIII or factor IX – downloadable from the WFH website [www.wfh.org](http://www.wfh.org).



When making an appointment – or when you have just arrived and are lying in the chair under the stadium light – here is a simple list of things these Guidelines recommend to remind your dentist or orthodontist:

- The type and severity of your haemophilia.
- All the medications you take and whether you have had factor, tranexamic acid or any other haemophilia related medication prior to your arrival.
- Whether you have:
  - An inhibitor
  - An infectious disease, such as viral hepatitis
  - A joint replacement
  - A venous access device (port).
- An opportunity to remind the dentist that deep injections, surgical procedures – particularly those involving bone (extractions, dental implants) – and regional local anaesthetic blocks should be avoided (where possible) as they may start a severe bleed.
- Details of your HTC.
- That you are not going to exsanguinate all over the surgery floor as soon as you open your mouth!

### Further reading

Scully C, Diz Dios P, Giangrande P. Oral care for people with hemophilia or a hereditary bleeding tendency. 2nd edn. Treatment of Hemophilia No 27. Montreal: World Federation of Hemophilia, 2008 – [www.wfh.org](http://www.wfh.org)

FitzGerald, Kirsten (Our Lady's Children's Hospital, Dublin, Ireland). Assessment of management of early caries management programs in children and adolescents with hereditary coagulation disorders. Presentation at WFH 2014 World Congress, Melbourne, 11-15 May 2014. ■

# RECIPES FOR HEALTHY LIVING

*Maria Wensing*

I felt both privileged and honoured to have attended the WFH 2014 World Congress in Melbourne! I arrived very early on the first day of Congress for a very important job: to help set up the 122 Flags of all the National Member Organisations! It struck me afresh, looking at the beautiful array of colourful flags, that we are all in this together - from all over the world - all united in this one cause, to work towards the goal of "treatment for all".

As I lined up the flags, I reflected on all the countries I'm connected to from across the globe, and this is true of many of us in Australia; we are such a wonderful mix! I reflected that out of all my family that I'm the only one to have landed with the haemophilia gene. One can feel most alone in this world having this disorder, but being at this Congress makes you realize you are not alone at all.

But there are far too many countries where there is little if no treatment at all for people living with haemophilia. The challenge remains to close the gap. There are many countries yet to be joined in as National Member Organisations and their flags to be added to the array of NMO Flags at future Congresses - countries like Myanmar and countless others. I look forward to the day when we will see this come to pass.

## RECIPES FOR HEALTHY LIVING

*Chair: Robyn Shoemark, Australia*

*Joann Deutsche, USA; Kristy Wittmeier, Canada; Andrew Selvaggi, Australia.*

I looked forward to this session as nutrition/healthy living are such important subjects for everyone and no less for a person with a bleeding disorder. In a world where there is

so much conflicting information on nutrition and supplements, I believe it is an area that requires extensive research and information for people with bleeding disorders, particularly where nutrition affects coagulation and quality of life.

Joann Deutchse's presentation on how nutrition affects coagulation was very informative. She addressed the importance of ferrous sulphate and gluconate to restore iron levels where they are deficient, and spoke about the importance of a diet rich in iron which includes foods such as leafy green vegetables, nuts and seeds. Joan also highlighted the questions about vitamin E and omega-3 fatty acids and their relationship to bleeding risks. She stressed that supplements are cause for concern and that food is always the safest choice!

Andrew Selvaggi's presentation was interactive, entertaining, informative and nothing short of inspirational. Andrew used colourful and easy to follow slides with a touch of comedy to present his life story, from a young boy with severe haemophilia, through his adolescence years, to where he is now as a healthy young man who works as a personal trainer.

Andrew shared his story since his diagnosis using quite explicit slides that highlighted the seriousness of his conditions:

- 130 hospital admissions
- 7 operations
- 445 joint muscle bleeds
- 5 major target joints
- Age 5-20 years spent 90% in wheelchair
- 30% school attendance.

The endless cycle of bleeds, recovery time and inactivity caused Andrew's weight to increase to an unhealthy

level. Faced with the prospect of never getting out of this vicious cycle, Andrew made a choice to turn his life around and change his medical condition with diet and physical activity.

It is hard to believe the change in Andrew in a few short years, as is evident from his slides. He is now is incredibly fit due to his regimen of physical exercise and healthy eating. This has paid enormous dividends on his joints and muscles with significantly decreased bleeds. His determination and motivation to get fit and healthy knew no bounds. As a personal trainer, Andrew focuses on weights and cardio and continues to inspire other young men with haemophilia to take up the challenge of a healthy lifestyle with regular physical activity and fitness, and encouraging balance in life.

One of Andrew's slide stated "You are what you eat". This slide depicting a hamburger, and someone looking like one, remains clearly in my mind and I'm sure, as with me, many in the audience felt challenged by what he was saying.

I found Andrew's presentation to be inspirational and ground-breaking. He made the impossible seem possible, the unbelievable believable, and the unreachable, reachable. A serious message filled with hope, delivered in a light hearted way with humour but with a kick to it, and a challenge to all of us listening.

**His last slide was this recipe:**

- 1 cup of exercise
- 2 cups healthy eating
- 1 tbsp of motivation
- 1 tsp determination
- And just a pinch of craziness. 



Jonathan Spencer is Executive Committee Member, Haemophilia Foundation Australia and President, Haemophilia Foundation Tasmania

# UP CLOSE AND PERSONAL

*Jonathan Spencer*

We're still searching for a cure for haemophilia; but a cure has been found for the loneliness and isolation from living with a bleeding disorder – it's foundations like the World Federation of Hemophilia (WFH) and in Australia, Haemophilia Foundation Australia! This was the sentiment expressed by Brian O'Mahony, former WFH President, when accepting his WFH Lifetime Achievement Award during the Congress Awards ceremony.

Overwhelmingly, this spirit of community is also my lasting impression of the 2014 World Hemophilia Congress in Melbourne, last month. Sure, the marvellous (if not unseasonal) Melbourne weather and the delightfully quirky and uniquely Australian entertainers at our cultural event helped the cause. However, for me, the feeling was best demonstrated where individual patients were willing, and sometimes keen, to share their personal experiences in a trusting and caring environment. Our local and national and international foundations help build this environment. Perhaps it's not so surprising that almost everyone in our worldwide community has similar experiences.

Often, as individuals, we can feel alone in dealing with intensely personal issues such as disclosure and how to deal with chronic pain. I attended two sessions showing how individuals deal with these everyday issues.

## **DISCLOSURE: WHEN, HOW AND WHO TO TELL ABOUT A BLEEDING DISORDER**

*Chair: Tony Roberts, South Africa*

*Brian O'Mahony, Ireland; Shirin Ravanbod, Iran; Neil Boal, Australia; Tony Roberts, South Africa.*

Brian O'Mahony's Irish experience is that disclosure has social, cultural and religious aspects and availability of treatment has an important impact on disclosure. Adequate treatment reduces isolation at school, improves employment opportunities and builds confidence to form relationships. In Iran, Shirin Ravanbod as a genetic carrier recounted her 22 years' experience of the stigma, anxiety with childbirth and social/family pressure that limit many disclosures. Whereas Neil Boal spoke of the Australian paradox where blood in sport may be seen as a badge of honour; however, particularly for related blood borne viruses, bullying and discrimination is still possible. Finally, Anthony Roberts explained the psychological aspects of disclosure where non-disclosure provides you power and control, while disclosure may lead to rejection.

Disclosure remains a strong talking point and experiences are mixed. It seems that one approach does not fit all circumstances or environments. The context and situation, along with our level of confidence and courage, will heavily influence the decision and timing of disclosure.

## **MULTIDISCIPLINARY MANAGEMENT OF CHRONIC PAIN**

*Chair: Ian d'Young, New Zealand*

*David Butler, Australia; Kate McCallum, New Zealand; Pamela Narayan, India; Sylvia von Mackensen, Germany.*

David Butler presented a challenging and provocative view on the management of chronic pain. With only one in 10 drugs effectively dealing with chronic pain, our



Congress Welcome Reception. Photo: WFH

community needs to do something about pain management. Pain cannot be cured – neurologically, pain is a signal, rightly or wrongly, of danger for our body tissues. The longer a pain exists the worse it hurts – eventually, altering the way we think. However, there is a neuroscience revolution involving a biopsychosocial approach to deal with pain signalling and changing our thoughts on pain. Such approaches have a far better response rate than drugs alone.

Kate McCullum endorsed the view that people with a bleeding disorder use progressively stronger analgesics as a first line choice and opioids work best for short-term (2-4 hour) acute or break-through pain, with weak long-term benefits. Pamela Narayan provided her experience that people with a bleeding disorder often self-medicate without advice from their treatment centre and, sometimes, are not able to distinguish between a bleed and joint pain. From a physical therapy perspective, functional restoration, rather than pain relief, should be the focus. Sylvia von Mackensen confirmed a psychological approach to pain management. Pain is always subjective and influenced by expectancy, control, fear and negative thoughts. While more research is needed there are non-medical methods to control pain.

The current approach to effective pain management is a combination of psychological and non-psychological interventions, involving pain education, psychological therapies, self-regulation and analgesics, as medicated – not on demand. ■

# REFLECTIONS ON THE PSYCHOSOCIAL DAY

Clare Reeves

An “ice breaker” is a great way to get people up and about, out of comfort zones and ready for an interactive, sharing day of work, fun and learning. It was with an “ice breaker” that Ed Kuebler, Social Worker from the USA got the ball going (literally). Approximately 100 people – psychosocial workers and community members from around the world - participated.

We began by breaking into several group circles and throwing a beach ball to one another. The multi-coloured beach balls had questions written on each coloured segment. When the ball was thrown you caught it and responded by answering one of the questions written on the ball. This simple exercise set the scene for the rest of the day and indeed the rest of the Congress for many of us. As a result we were more able to recognise the differences in each other, our different cultural backgrounds our different care and service deliveries. And in glimpsing our differences we were then able to see a little more clearly through multicultural, multitasked, globally-focused eyes. And the differences became the connection and the desire to strive to communicate globally as psychosocial workers within the global bleeding disorder community.



Social worker Kate Lenthen with the beach ball  
Photo: Leonie Mudge

## TRANSITIONING THROUGH THE LIFE STAGES

### Aspects of life transition in patients with haemophilia: Physician's perspective

*Alessandro Gringeri, Austria*

Dr. Gringeri highlighted aspects focusing on childhood to adolescence, adolescence being, in his opinion, a “most difficult time.”

He expanded on:

- Timely on-demand treatment
- Bleeding recognition
- Adherence to prophylaxis
- What affects compliance?
- What is the difference between adherence and compliance?
- Education and training and the importance of physical exercise.

### Aspects of life transition in patients with haemophilia: Psychologist's perspective

*Moana Harlen, Australia*

This session started with the question: “What helps children cope with life transitions?” From a development psychology perspective the acquisition of competent emotional regulation (ER) skills is considered to be essential for adaptive functioning. And what is ER, or Emotional Regulation? It refers to the individual's ability to cope with, control and modify their emotional responses to environmental stimuli. Emotional Regulation was only one aspect of Moana's presentation, but one I found most interesting. She also went on to give two very interesting case studies and

highlighted aspects of a child's developmental outcomes in relation to physical, emotional, social, spiritual and cultural diversities.

### Aspects of life transition in patients with haemophilia: Social worker's perspective

*Maureen Spilsbury, Australia*

This was an extremely interesting and thorough presentation commencing with “defining transition” and some interesting quotes about transition:

- “Only the wisest and stupidest of men never change.” - Confucius
- “I can't change the direction of the wind but I can adjust my sails to always reach my direction.” - Jimmy Dean.

Maureen discussed how social workers, psychologists and others working within the haemophilia community can offer valuable support as people navigate stages of life by remembering:

- The way in which each individual experiences like transitions is dependent on a range of issues related to their specific situation.
- There is not necessarily a one size fits all.
- We are all unique.

And in conclusion, we were reminded that:

- Life transitioning begins at birth and only ends at death.
- People with haemophilia can experience the same major and minor life transitions as the general population.

>>

## Aspects of life transition in patients with haemophilia: Patient's perspective

*Dustin Bridges, Australia*

This was a very insightful talk centred on Dustin's own journey with haemophilia. Dustin received so many questions during the session and at morning tea these questions continued. One question asked of him during the session was "What would you tell teenagers about compliance, and regular self-treating?" His response was wise and insightful, from one who has truly been there: "It's difficult to tell teenagers anything!!" All part of growing and learning by experience.

## Aspects of school and academic achievement in people with haemophilia

*Tony Roberts, South Africa, and Noorallah Taheri, Iran*

These talks centred on opportunities, or lack of them, for young people with bleeding disorders, globally, within the school systems. Absenteeism, lack of knowledge and understanding, availability/unavailability of product and treatments are all contributing factors. As Tony Roberts put it, "your chances of optimal scholastic achievement is dependent to a large extent on how well your haemophilia is treated."

## How to work with children on critical transitional life events

*Frederica Cassis, Brazil*

Frederica presented aspects of transition particularly in the early years and progressing to school. She showed how "flash cards" can be helpful educational tools when working with children and families in explaining haemophilia, preparing for prophylaxis, self-infusion and port-a-cath.

After three more presentations, the Psychosocial Day concluded with a "meet and greet" hosted by Australian and New Zealand psychosocial workers and sponsored by HFA and HFNZ.

Throughout the day and then throughout Congress, at evening events and over meals outside the Congress those of us attending were able to meet up, exchange ideas, and learn from each other. Being present at Congress refreshed, challenged and enthused me. What seemed to be consolidated for all was the importance of the psychosocial component within a multidisciplinary team and comprehensive care model of service delivery. ■

# BUDDY AWARDS LAUNCH



Sam making the first nomination with his wife and Colleen McKay

Photo: Novo Nordisk

There were many exciting announcements at this year's World Federation of Hemophilia Congress, which took place over May 11-15 in Melbourne. From new research advancements through to investment announcements there were many things to celebrate at the congress.

Amongst the new initiatives was the launch of the Buddy Awards to an enthusiastic audience hosted by Sharon Caris, Executive Director of HFA, and Colleen McKay, Manager of Outreach Services Haemophilia Foundation New Zealand (HFNZ). The Buddy Awards are sponsored by Novo Nordisk to recognise the significant medical, emotional and practical support provided by family, friends, healthcare professionals, teachers and others, to people living with bleeding disorders. Global Product Manager, Dr Peter Ramge, presented a donation to HFA and HFNZ to help promote awareness of the Buddy Awards.

"These annual awards celebrate the invaluable contribution these caring people make while also drawing public attention to the challenges of living with a bleeding disorder," said Sharon Caris.

The lack of public awareness of bleeding disorders means that the important role of families and friends often goes unnoticed.

## AWARD NOMINATIONS

Alister (Sam) Bradley from New Zealand marked the official opening by submitting the first nomination, for his wife, to recognise the continued support she provides. After his presentation, the launch was closed with an impromptu song from the audience, a very soulful rendition of 'You Are My Sunshine'.

If you know someone who deserves recognition, download and complete the nomination form which will soon be available at

[www.novonordisk.com.au](http://www.novonordisk.com.au) and email it to: [buddyawards@cube.com.au](mailto:buddyawards@cube.com.au).

Nominations close **29 August 2014**. ■

# “WHAT’S YOUR DREAM” COLOURING IN COMPETITION

Haemophilia Foundation Australia with the support of Octapharma Group ran an exciting colouring in competition. The entries were judged and winners announced at the WFH World Congress.

We received over 500 entries from 18 countries and were very impressed with their creativity.

Congratulations to the following winners –

## Category A – 4 and under

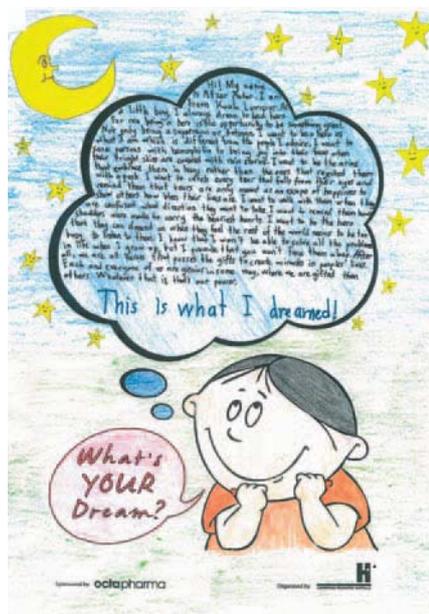
- 1<sup>st</sup> Zarzuri, Argentina
- 2<sup>nd</sup> Louisa, USA
- 3<sup>rd</sup> Isabella, Australia

## Category B – 5-9 years

- 1<sup>st</sup> Afzar, Malaysia
- 2<sup>nd</sup> Thom, Germany
- 3<sup>rd</sup> Putri, Singapore

## Category C – 9-11 Years

- 1<sup>st</sup> Rios, Argentina
- 2<sup>nd</sup> Guilherme, Brazil
- 3<sup>rd</sup> Henry, Singapore



All winners have been notified. Thank you to everyone who participated. H

# POLICY NEWS

Suzanne O'Callaghan and Hannah Opeskin

You may have noticed that HFA's community surveys on hepatitis C have been coming thick and fast lately. There have been several important government requests for information and it made the HFA submissions so much stronger to have specific feedback and personal stories from community members. Thank you to all the people who responded!

In May and June 2014 HFA made submissions on:

- The Senate Inquiry into out-of-pocket health care costs – the HFA submission included case studies relating to living with hepatitis C and a bleeding disorder.
- The draft National Hepatitis C and HIV Strategies – raising the special issues of living with multiple complex health conditions experienced by people with bleeding disorders.
- Evaluation of simeprevir and sofosbuvir for listing on the Pharmaceutical Benefits Scheme for the treatment of hepatitis C.

Sofosbuvir and simeprevir are part of the new wave of direct acting anti-viral (DAA) hepatitis C drugs. In clinical trials they had very high success rates, few side-effects,

and shorter treatment courses (eg, 12 or 24 weeks). They need to be taken in combination with other medications (eg, interferon, ribavirin) to be effective. Professor Ed Gane from New Zealand explained more about these new DAAs at a recent conference in Brisbane – [www.tinyurl.com/new-hep-c-treatments](http://www.tinyurl.com/new-hep-c-treatments). We will report on the outcome of this evaluation when the decision is made available later in the year.

## GP MANAGEMENT PLANS

For someone with a bleeding disorder a GP management plan aims to help the patient and the GP to work collaboratively on their health care and manage their other health conditions taking their bleeding disorder into account. We recently attended a Consumers Health Forum meeting to discuss GP Management Plans and contribute to a government review. The discussion focused on the problems experienced when patient uses a GP management plan and has to navigate the health care system. Many experiences reported by those attending were quite positive but particularly centred upon having a good relationship with a GP. #

# WORLD HEPATITIS DAY

World Hepatitis Day will be marked globally on 28 July 2014.

**This year the focus will be on checking your liver health regularly.**

As a Partner in the national World Hepatitis Day Campaign, HFA is working with Hepatitis Australia on the annual national awareness campaign and is committed to improving liver health and reducing hepatitis C stigma and discrimination in Australia.

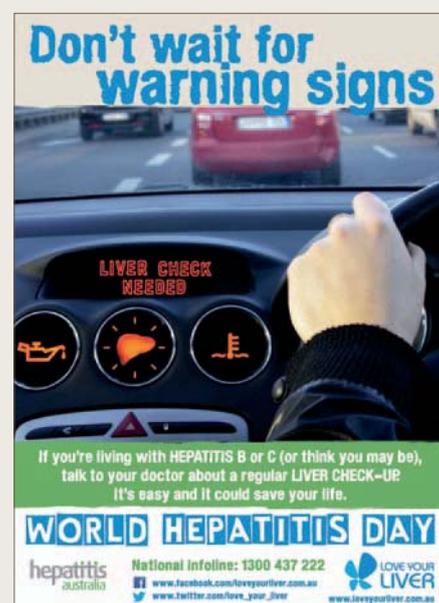
The theme this year is particularly relevant to people with bleeding disorders and chronic hepatitis C so you will see more about this in HFA communications like the HFA website and Facebook page, as well as in local Foundation newsletters.

A copy of the Liver Health Fact Sheet and poster has been included in this issue of *National Haemophilia*.

Keep your eye on the Love Your Liver web site ([www.loveyourliver.com.au](http://www.loveyourliver.com.au)) for this year's activities, as well as tips on looking after your liver, delicious liver-friendly recipes, information about your liver and how it works, and the latest research on liver health.

If you would like to be involved in local events, contact your State or Territory Haemophilia Foundation or your local hepatitis organisation to find out about the activities taking place in your area.

More information is available at [www.hepatitisaustralia.com.au](http://www.hepatitisaustralia.com.au). #



# HAEMOPHILIA FOUNDATION AUSTRALIA RESEARCH FUND

## NEW FUNDING ROUND OPEN!

\$20,000 is available for medical, scientific or social research to improve outcomes for people with haemophilia, von Willebrand disorder or other related inherited bleeding disorders, and/or those with medically acquired blood borne viruses.

The funding round is for research projects to commence in the 2014-2015 financial year.

Closing date:  
15 October 2014

For further details and application form:

Go to the HFA web site -  
[www.haemophilia.org.au](http://www.haemophilia.org.au)

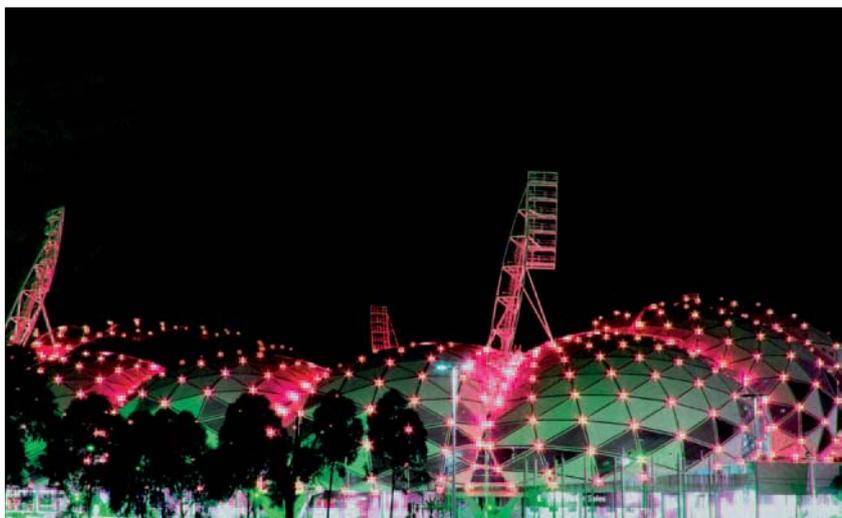
or contact HFA

A 1624 High St, Glen Iris 3146

T 03 9885 7800

E [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) 

## WORLD HAEMOPHILIA DAY 2014



On April 17 this year HFA and other World Federation of Hemophilia National Member Organisations around the world celebrated World Haemophilia Day.

The message was that an estimated 1 in 1000 people have a bleeding disorder - almost seven million men, women and children globally - but 75% of them are undiagnosed and receive little or no treatment.

AAMI Park in Melbourne turned its lights red to mark the day.

In Canada and the US, in an impressive demonstration of solidarity, the CN Tower in Toronto, the Langevin Bridge in Calgary, the Leonard P. Zakim Bunker Hill Bridge in Boston and both the US and Canadian sides of the Niagara Falls also turned red.

At HFA we used our Facebook page and Twitter to promote the Close the Gap campaign run by the World Federation of Hemophilia – this campaign aims to close the gap of treatment and care worldwide through awareness and fundraising. It was a great way to engage our supporters around the world. 

# RED CAKE DAY ~ HAEMOPHILIA AWARENESS WEEK 12 – 18 OCTOBER 2014



**Haemophilia Awareness Week** is an opportunity for Haemophilia Foundations and other organisations, as well as individuals and families to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disorder and related inherited bleeding disorders throughout Australia during the week of **12 – 18 October 2014**.

HFA is calling on our friends and supporters to help us celebrate Haemophilia Awareness Week by taking part in **Red Cake Day!**

It's easy... all you have to do is bake some delicious red cakes or cupcakes, decorate them, and share them with your friends or work colleagues in exchange for a donation or a gold coin.

You could take them to work, school, have a cake stall or simply host an afternoon tea with your nearest and dearest family and friends. Not only will you be having a delicious morning tea but you'll be helping raise funds and spread the word about haemophilia and other inherited bleeding disorders!

Then, simply send the donations to Haemophilia Foundation Australia. All funds raised will go to a range of programs and services run around the country.

Last year we raised over \$15,000 from Red Cake Day activities and we see this as a very simple fundraising opportunity that all our friends and supporters can easily participate in. Please help us.

The promotional items ordering system will be online at the end of July. To receive an alert when this is open email your details to [Natashia ncoco@haemophilia.org.au](mailto:Natashia.ncoco@haemophilia.org.au).

For more information on Haemophilia Awareness Week and Red Cake Day visit

[www.haemophilia.org.au/redcakeday](http://www.haemophilia.org.au/redcakeday) or

call HFA on **1800 807 173** or

email [Natashia ncoco@haemophilia.org.au](mailto:Natashia.ncoco@haemophilia.org.au)

Like Red Cake Day on Facebook -

[www.facebook.com/RedCakeDay](http://www.facebook.com/RedCakeDay) #

## 2014 'CHANGING POSSIBILITIES IN HAEMOPHILIA®' GRANTS

Applications are now open for the 2014 'Changing Possibilities in Haemophilia®' grants program. Through the program, \$50,000 in funding will be available for unique projects advancing haemophilia care.

Now in its third year, organisers of the 'Changing Possibilities in Haemophilia®' grant program are calling for entries from healthcare professionals and allied health professionals currently providing haemophilia care in Australia. To be successful, applicants are being encouraged to think outside the box and consider new and novel initiatives that aim to support patients beyond their routine treatment needs.

"Because haemophilia is a rare and lifelong condition, people living with the condition face more than medical issues, and so there's a lot of scope for applicants to employ creativity and develop programs that can make a real difference" said Sharon Caris, Executive Director of Haemophilia Foundation Australia (HFA) and one of the judges who will assess applications.

'Changing Possibilities in Haemophilia' is a competitive grants scheme established by Novo Nordisk to provide funding for practical initiatives or programs that seek to advance haemophilia care in Australia.

Submissions for the 2014 'Changing Possibilities in Haemophilia' grants will be accepted until **Thursday 31 July 2014**.

This initiative is open to healthcare professionals and allied health professionals including, but not limited to, nurses, physiotherapists, psychologists and social workers.

For more information and to download an application form, visit: [www.changingpossibilities.com.au](http://www.changingpossibilities.com.au)

# YOUTH ADVOCACY IN ACTION

*Jenna Lovell*

I am so grateful to have attended WFH Congress 2014 in Melbourne this year. As someone new to this community (but not to my diagnosis) this was only my second major bleeding disorder community event (the first being the last HFA national conference in 2011).

One of my favourite parts of bleeding disorder community events is getting to meet other people in our community, and Congress 2014 was no exception. There's really nothing else like it – each and every one of the people in our community I meet, regardless of age, gender, diagnosis, whether they're the first in the family or the fifth, or even country of origin despite all the differences in care across the world; all of the people I meet are kind, warm, genuinely empathetic and people who understand what it is like living with a bleeding disorder. As someone who spent the first decade of my diagnosis not being connected with this community, I love seeing it in action! To add in the privilege of being the host country to 4000 people from around the world was astounding. We are truly part of an inspiring and dedicated group. Throughout the week, in both official activities like sessions, the HFA Youth Meet and Greet as well as outside of the official activities, I caught up with friends, made new connections and was constantly inspired by the people dedicated to bringing our community together to learn and connect.

Of course, the sessions were also a privilege to attend. While some of the more medical ones were quite technical, the psychosocial sessions were very informative and relatable. It was these sessions in particular that allowed both the formal speakers as well as audience members who asked questions to share their personal experiences in a range of areas relating

to living with a bleeding disorder. Another young Australian, Andrew Selvaggi, presented in a session called "Recipes on Healthy Living: Beyond the Vegemite Sandwich" on how his diet and lifestyle aid in bleed management and healing. As someone who also chooses to eat, exercise and live my life in a way that helps manage my own bleeds, I found this session very interesting.

## PRESENTING AT THE CONGRESS

I was invited to speak at a session myself by WFH after presenting at an Advocacy in Action workshop last year in Montreal. WFH staff invited me to present on Australia's recent youth advocacy and engagement activities, which I have been fortunate enough to be involved in. In my presentation, I shared the creation process for our youth website, Factored In, as well as the origins and implementation of the national youth mentor network. I presented alongside two other young

people, Uros from Slovenia and Miguel from Mexico, who shared their stories of engaging young people in our community. I really enjoyed speaking at Congress, and would love to do it again.

## FUTURE CONGRESS AND CONFERENCES

To anyone who is thinking about attending either our next national Conference on the Gold Coast next year, or one of the upcoming Congresses in either Orlando, USA in 2016 or in Glasgow, Scotland in 2018, You'll have unparalleled access to specialists and experts in every field of caring for and treating a person with a bleeding disorder, you'll make contacts and friends with people who just get what it's like to live with the same things you do either as a bleeder or a carer. Let's not forget you'll also get to travel internationally! I can't wait to see what Orlando holds! #



Jenna being interviewed at Congress. Photo: WFH

# THROUGH THE EYES OF A YOUTH FELLOW

Tim Demos

I was lucky enough to be nominated by Haemophilia Foundation Australia (HFA) and accepted by the World Federation of Haemophilia (WFH) to attend both the World Congress and the WFH Global National Member Organization (NMO) Training as a Youth Fellow. The entire event turned out to be one of the most amazing experiences I've been involved in - this is a very brief summary of my time as a Youth Fellow.

## NMO TRAINING

The NMO training at Creswick was focused around empowering national haemophilia organisations with the skills and capacity to develop their future leaders, lobby effectively with governments, and addressed the role of pharmaceutical companies in funding. As a representative for HFA I was one of many young people that attended from countries all over the world including Tunisia, Argentina, Austria and Mexico. The weekend was an intense experience with each day full of plenary talks and breakout sessions with a few buffet meals in between. The calibre of people in attendance was really humbling; I got to meet so many other people with haemophilia - both males and females - who have achieved amazing feats such as speaking multiple languages, completing medical studies, and engaging in employment that re-defines what people with haemophilia can do. I heard so many people say they don't speak English when they were genuinely more fluent than me! This was my first exposure to the international haemophilia community and it really opened my eyes. Growing up in Australia with access to prophylactic clotting factor all my life meant it was a shock to see people my age who have never had access to prophylaxis and now live with severe limps and fused joints.



WFH Youth Fellows in Creswick. Photo: WFH

Previously I have taken certain aspects of my management for granted, the full time dedicated care teams, access to safe clotting factor and, most of all, the extensive support networks. These are all things others across the world can only imagine.

## CONGRESS

The Congress itself was an exciting culmination of promising research, best treatment principles, new management techniques and strategies to close the gap between haemophilia management disparities across the world. The various presenters and representatives from numerous countries showed me that everything the haemophilia community has today in terms of funding and recognition is the direct result of many years of lobbying and advocacy.

It's an exciting time to be involved with haemophilia with new long lasting products around the corner, but it's vital that the next generation understand how far things have come in the past 20 years and how it can be improved further in the future.

One of the main messages I took away from a number of presentations is the importance of exercise and a healthy lifestyle in haemophilia care. While we are incredibly privileged to have access to clotting factor in Australia, this alone is not enough to maintain a healthy body and is only one part of the puzzle.

The NMO training and World Congress was an amazing experience and one that I will always remember. I formed friendships with young people involved in haemophilia all over the world and learnt things about the condition I previously had no idea about. If I can leave you with one thing I have learned from this entire experience, it's to seek out one of the many opportunities to become more involved in the Australian and international haemophilia communities.

Don't wait for an invitation like I did but rather contact your state or national based haemophilia organisation, get involved and find out how you can meet incredible people and have amazing opportunities like I was lucky enough to during the World Haemophilia Congress. #



# YOUTH AT CONGRESS

*Hannah Opeskin*

Prior to the World Federation Hemophilia (WFH) 2014 Congress, Haemophilia Foundation Australia (HFA) held a weekend for people affected by bleeding disorders and aged between 18-30 from around Australia who would also be attending the Congress. HFA asked Tim Marchinton and his team at Purple Soup, an adventure therapy organisation, to facilitate the weekend.

Almost 30 young people attended the weekend, designed to urge youth delegates to move out of their comfort zone and meet other young people with bleeding disorders. The Youth Meet and Great weekend was set along the banks of the Yarra River in Melbourne and involved a variety of activities including movie making, cupcake decorating and mock poker tournaments.

A challenging race around the CBD was also held where teams of youth delegates had to answer questions such as how many light poles are there at Parliament House.

Many international youth delegates who attended the National Member Organisation (NMO) training before Congress also joined our Australian youth delegates for the cupcake decorating, which was judged by some members of the WFH Executive Committee and Frank Schnabel IV, grandson of the Founder of the World Federation of Hemophilia, before the Congress Opening Ceremony on the Sunday night. While many of the Congress sessions were oriented towards health professionals, there were also youth sessions in which our Australian youth were actively engaged.

It was a great experience to see many of our young Australians with bleeding disorders in one place together. It was also good to see our Australian youth interact with other youth delegates from around the world and make new and lasting friendships throughout Congress. From attending the Congress sessions and learning new information to watching a local AFL

match, all the youth delegates made sure they took the most they could from the week. Many young women with a bleeding disorder met other young women in a similar position as them for the first time in their lives. The youth weekend also gave partners of people with a bleeding disorder insight into the small but vibrant Australian youth bleeding disorders community.

Our youth leaders and mentors intend to work with HFA to continue to foster their new friendships and connections and to ensure youth affected by a bleeding disorder in Australia have a chance to stay connected and involved. ■



Cupcake decorations by youth delegates



Cupcake decorating



Youth competing in a race around the CBD

# YOUTH NEWS

## ETHAN

I thought the youth weekend before Congress organised by Purple Soup was amazing and a lot of fun. I enjoyed the Congress immensely because I love meeting new people with haemophilia and other bleeding disorders. I learnt a little bit more about von Willebrand disorder and it was nice to talk to girls with bleeding disorders and understand a little bit more about their lives. Most of the sessions gave me more information to take home although I particularly enjoyed the youth session presented by Jenna from Australia which showed what youth with bleeding disorders are doing locally and all around the world. Attending the Congress made me want to get more actively involved in the bleeding disorders community.

## Katherine

I liked meeting new people looking at all the things involved in making sufferers lives a bit easier. I learnt about the rarities of particular factors and the processes of diagnosing and the help that is available for the people affected.

## Sam

The things that I found most enjoyable about the Congress was meeting new people from around the world and making friends, I learnt a lot about the state of youth involvement around the world which is important to me. There were several sessions on healthy eating and the importance in relation to haemophilia which I found very interesting.



Youth decorating cupcakes

# FEEDBACK FROM YOUTH DELEGATES AT THE WFH 2014 WORLD CONGRESS



Youth dressed as superheroes for a flash mob during Congress

## Jade

May 2014 held a once in a lifetime experience for me. A chance to travel to the World Congress for haemophilia, a chance to meet amazing people from all over the world, a chance to meet others just like me and a chance to be in a room with thousands of people that actually just got it!

The Congress enabled me the opportunity to further develop my knowledge surrounding bleeding disorders and in particular von Willebrand disorder.

I was also given the opportunity to be a part of the Youth Meet and Greet program. I not only met incredible strong people with bleeding disorders but I met people of similar ages and experiences and I also got to meet partners of these amazing people as well. This rare occasion was truly awakening to be able to interact with others, learn and be inspired; but for my husband who has always been so supportive and understanding it was an opportunity where he could also relate to those of similar experiences in supportive roles.

This Congress opened my eyes to new technologies and new developments in the world of bleeding disorders and although it was hard to see just how much is needed to get VWD up there with other bleeding disorders such as haemophilia, I did come out with a positive outlook. VWD is a major area where research is lacking with high rates of severity and type misdiagnosis as well as undiagnosed VWD. More effective treatments for VWD and even the use of prophylaxis have all been recognised as an area for future research. This is an exciting revolution for me and I am excited at the possibilities this holds for not only our community but for future generations.

# CALENDAR

## Haemophilia Awareness Week

12-18 October 2014

Tel 03 9885 7800

Fax 03 9885 1800

Email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

[www.haemophilia.org.au](http://www.haemophilia.org.au)

## World Haemophilia Day

17 April 2015

[www.wfh.org/whd](http://www.wfh.org/whd)

## 17<sup>th</sup> Australian & New Zealand Conference on haemophilia & related bleeding disorders

1-3 October 2015

Gold Coast

Tel 03 9885 7800

Fax 03 9885 1800

Email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

[www.haemophilia.org.au](http://www.haemophilia.org.au)

## CORPORATE PARTNERS

Haemophilia Foundation Australia (HFA) values the individuals, philanthropic trusts and corporations which have made donations to education activities and peer support programs and Corporate Partners that sponsor programs to enable HFA to meet its objectives of:

- advocacy and representation that improves access to treatment and care for people with bleeding disorders
- education and peer support activities that increase independence and the quality of lives of people with bleeding disorders, and their families
- encouraging clinical excellence in haemophilia care, and promoting research.



biogen idec

CSL Behring



## SAVE THE DATE!

17th Australian & New Zealand Conference on haemophilia & related bleeding disorders

1 - 3 October 2015

Gold Coast

Tel 03 9885 7800

Fax 03 9885 1800

Email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

[www.haemophilia.org.au](http://www.haemophilia.org.au)

## 17<sup>TH</sup> Australian & New Zealand Conference on haemophilia & related bleeding disorders



1 - 3 OCTOBER 2015 • GOLD COAST



NATIONAL HAEMOPHILIA is a publication of Haemophilia Foundation Australia. Every effort is taken to ensure accurate and relevant content, however opinions expressed in NATIONAL HAEMOPHILIA do not necessarily reflect those of the Foundation or the editor, nor is any information intended to take the place of advice from a qualified medical practitioner or health professional. Haemophilia Foundation Australia does not endorse or assure the products, programs or services featured in NATIONAL HAEMOPHILIA and does not make specific recommendations for any products, programs or services. We welcome reproduction of articles or quotations from NATIONAL HAEMOPHILIA on the understanding that acknowledgement is made of NATIONAL HAEMOPHILIA as the source. Haemophilia Foundation Australia acknowledges the funding and assistance received from the Commonwealth Department of Health and Ageing which makes this publication possible.